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TITLE: Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer

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14. ABSTRACT Women at increased risk of Hereditary Breast and Ovarian Cancers (HBOC) and their families face dilemmas about testing, risk management and family dissemination of results. They face problems regarding the accuracy of the information they have received, difficulties accessing new information and specialized services, and resistance and misinformation from inadequately informed health care professionals in the community. Thus, they are forced to develop their own informal means of individual and communal coping and to identify and access appropriate formal services without guidance. The FORCE website (www.facingourrisk.org) serves important functions in the sharing of information, provision of support and active problem-solving, and in normalizing and validating the women's response to their predicament. This project is intended to yield the basis for clinically useful tools to reach out to these women and better address their unmet needs. It will identify the specific tasks with which they need assistance and the forms that competent coping takes. Results will give impetus to new clinical, public policy, and research agendas for women and their families living with inherited risk of cancer. To date, we have combined quantitative and qualitative analyses to identify and examine one of the most frequently discussed topics on the message boards; decision-making regarding the use of hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). Other papers in progress include the decision to undergo prophylactic mastectomy and subsequent decisions surrounding reconstruction, the lived experience of prophylactic mastectomy, and sense of self and renegotiation of identity following prophylactic mastectomy.					
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Introduction

Women at increased risk of Hereditary Breast and Ovarian Cancers (HBOC) and their families face dilemmas about testing, risk management and family dissemination of results. They face problems regarding the accuracy of the information they have received, difficulties accessing new information and specialized services, and resistance and misinformation from inadequately informed health care professionals in the community. Thus, they are forced to develop their own informal means of individual and communal coping and to identify and access appropriate formal services without guidance.

Facing Our Risk of Cancer Empowered (FORCE) is a nonprofit organization and associated website (www.facingourrisk.org) devoted exclusively to the community of women at risk for HBOC. FORCE serves important functions in the sharing of information, provision of support and active problem-solving, and in normalizing and validating the women's response to their predicament. This project involved evaluation of the activity and content of the FORCE website.

All data was collected online and is completely anonymous. The project sampled message board discussions for emergent issues and themes, recurring problems, and strategies for successful coping. Procedures included formal content analysis of archived threads and specific queries posed to a representative consumer board of women participating in FORCE activities. Additional analyses focused on the social structure of the FORCE community, how it is used by members of HBOC families, and how it reflects the unmet needs with respect to the medical system.

This project was designed to yield the basis for clinically useful tools to reach out to these women and better address their unmet needs. It identified the specific tasks with which they need assistance and characterize forms of competent coping. Results give impetus to new clinical, public policy, and research agendas for women and their families living with inherited risk of cancer.

Body

This project was approved for data collection on May 17, 2004. Tasks 1 and 2 were completed in the first six months of the project. We convened meetings between the investigator team and Sue Friedman of F.O.R.C.E., developed a schedule of regular contacts between the investigator and advisory board, and set up procedures for conference calls with F.O.R.C.E. In lieu of a study listserv, we maintained regular telephone and email contact among the investigators and F.O.R.C.E. We hired research assistants and downloaded more than 8,600 separate threads appearing on the FORCE message boards between August 1999 and September 2004. We converted these HTML files to RTF format as searchable text documents for use with our analytic software program.

A software consultant advised the investigator team that new software, QSR-N-VIVO had superseded the NUD*IST software that we had been prepared to use for textual analysis. N-VIVO incorporated all of NUD*IST's key features, but had the advantage of being more user friendly. Key members of the research team attended training sessions to become proficient in N-VIVO data management and analyses. In addition, we were fortunate to be able to forge a collaboration with a senior qualitative sociologist who specializes in women's health and genetics—specifically issues related to HBOC. The combined efforts of our study investigators with expertise in qualitative and/or

quantitative methodology facilitated detailed analyses of textual data with a degree of precision often lacking in purely qualitative research. Task 3 was accomplished in Months 6-36 with the creation of index trees and coding schema for each content area. Initial quantitative analyses identified the themes of message board threads with the highest frequency and greatest continuity of activity and we prioritized these themes for further analysis in consultation with Sue Friedman. Her input was such that it warranted a co-authorship on the resulting papers.

Initial quantitative analyses identified the themes of message board threads with the highest frequency and greatest continuity of activity. We then combined quantitative and qualitative analyses to identify and examine the most frequently discussed topics on the message boards, which are as follows:

1) The first area investigated was decision-making regarding the use of hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). The basic dilemma was that women opting for PO as a risk reduction strategy experienced an intense artificial menopause and needed to decide whether to use temporary hormone replacement therapy to manage symptoms. The medical-scientific community was divided in its advice and, in particular, there was concern about whether HRT would undo the risk reduction achieved by PO, although there was little basis for estimating the extent of this effect. We downloaded relevant posts and performed content analyses. Our basic analytic strategy, also followed in our subsequent efforts, was to assemble and sort relevant posts and examine them for evidence of a priori themes, integrating them with new themes derived from the posts. Our initial ideas were revised and refined according to the content revealed by these qualitative analyses. Posts were then reexamined in an iterative fashion, adding explanatory detail and support for both revised a priori themes and the themes generated by the qualitative analysis. Results were presented at the *International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer* and were well received. A manuscript based on this presentation, entitled *Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board* appeared in the journal *Psycho-Oncology*. The article is enclosed in the appendices to this report. The abstract is as follows:

The FORCE (Facing Our Risk of Cancer Empowered) website is devoted to women at risk for hereditary breast and ovarian cancers (HBOC). To understand the unique health concerns and emotional support needs of these women, we examined threads on the /FORCE/ archived message boards with relevance to the broader HBOC community. We report on a thread discussing the controversial decision to use hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. Twenty-nine women posted 177 messages over 7 months. Two main groups of women posted: 1) Women who were BRCA+, had completed PO, and were debating or adjusting their HRT options in terms of optimizing both quality and quantity of life. 2) Women who were BRCA+, were contemplating PO, but wanted to better understand the potential physical and psychological consequences of surgical menopause before deciding. Frustrated by physicians' lack of knowledge and contradictory media articles about the long-term consequences of HRT in BRCA+ women, they sought

resources, emotional support and specific experiential knowledge from each other and generated a unique sense of community and a high level of trust.

Consistent with Task 5, we posted a draft of the manuscript on the FORCE website, and received laudatory, but few substantive responses. We therefore asked Susan Freidman to convene a smaller advisory board. They were helpful in clarifying the strong sentiment concerning the advantages of prophylactic surgery that was evident in postings at the chatroom. They also suggested that the article adopt pseudonyms for the pseudonymic screen names that the women had used in their postings. We accepted this and modified the manuscript and followed this policy in subsequent ones.

2) The second issue under investigation involved the decision to undergo prophylactic mastectomy (PM) and subsequent decisions concerning breast reconstruction. Themes in the content of women's communications on the FORCE message board were examined to identify psychosocial and physical concerns surrounding the decision to undergo prophylactic mastectomy with or without reconstruction, the processes involved in such decision making, and the impact of their decisions on quality of life. Analyses of 203 messages were conducted using QSR N-Vivo, a qualitative software program. Findings suggested that women grieve during the decision process, feel confident in their choices, feel relieved after surgery, and feel empowered by the process of taking control of their bodies and future health. An oral presentation, *Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board*, was delivered at the 2006 Society of Behavioral Medicine annual meeting. The presentation discussed bilateral prophylactic mastectomy (BPM) as a preventive strategy available to women with BRCA mutations. A manuscript was prepared and has now appeared in the *Journal of Genetic Counseling*. The abstract is as follows:

The Facing Our Risk of Cancer Empowered (FORCE) website is devoted to women at risk for hereditary breast and ovarian cancers. One of the most frequently discussed topics on the archived message board has been prophylactic mastectomy (PM) for women with a BRCA1/2 mutation. We reviewed the messages, over a 4 year period, of 21 high risk women and their "conversational" partners who originally posted on a thread about genetic testing, genetic counseling and family history. We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. The women sought emotional support, specific experiential knowledge and information from each other. They frequently found revealing their post PM status problematic because of possible negative reactions and adopted self-protective strategies of evasion and concealment outside of their web-based community. The FORCE message board was considered to be a safe place in which the women could be truthful about their choices and feelings. Results are discussed in terms of Goffman's concepts "stigma" and "disclosure" and Charmaz's concepts "interruptions," "intrusions" and a "dreaded future."

3) The third issue investigated was the women's use of genetic counselors and mental health professionals throughout the decision making process concerning genetic testing and risk reduction strategies and in their subsequent adaptation. Text searches of the FORCE archived message boards were carried out using keywords "psych*, shrink, therap*, counsel*, genetic counsel*". To limit the scope of the examination, we excluded posts exclusively on psychiatric

medications, or posts focusing solely on mental health afflictions, such as anxiety or depression.

As the goal was to examine women's attitudes toward and usage of mental health care and genetic counseling, posts resulting from the search were further culled to include only those involving experiential information relating to mental health care or genetic counseling. Posts were categorized in separate documents as "mental health care" or "genetic counseling" related. As there were a large number of posts on genetic counseling, we further eliminated all posts which mentioned simply going to a genetic counselor, or suggesting that another women seek a genetic counselor. This yielded the final data set: 779 posts on genetic counseling, 332 posts on mental health care. Irrelevant posts (those that did not focus on the women's qualitative experiences with genetic counseling and mental health care) were removed, yielding 411 posts on genetic counseling and 259 posts on mental health care. A manuscript has been prepared and is being finalized for submission to *Psycho-Oncology*. Its abstract:

This paper investigates the situations in which women from hereditary breast/ovarian cancer families (HBOC) seek help from genetic counselors (GC), mental health professionals (MHP) or peers. Mental health professionals (MHP) and genetic counselors (GC) have separate occupational histories and different primary goals which overlap to some extent. We analyzed messages from 159 women who posted under screen names on the FORCE archived message board between August 1999 and April 2004, plus 29 posts from anonymous posters. We used a mixed method design, combining quantitative and qualitative approaches. Quantitative analyses involved tallying how many women posted in various categories and the content of posts dealing with specific themes. Qualitative analysis included coding and identification of recurring themes, using close reading and hand coding of the data. In general, women tended to seek information at the beginning of the HBOC risk management process, and were at this time, more likely to access genetic counseling because the main goals of GCs are to present genetic information and reduce misinformation, explain individual client's risk for developing a genetic based condition, present options for reducing risks, and offer support thereby reduce their clients' anxiety. Later in the process, when preparing for medical procedures, recovering from surgery, or coping with body image or sexuality issues, women appear to be in need of additional emotional support, rather than information, and seek the services of mental health providers. The main aims of mental health professionals, few of whom have training in genetics, are to reduce anxiety and depression, help their clients understand themselves better and to learn to cope with "the hand that life deals them". Peers have a level of personal experience and anecdotal advice that professionals often lack, making web-based peer input a valued addition of garnering information and support for many women on the FORCE message board.

4) The fourth issue investigated was the lived experience of prophylactic mastectomy and related issues e.g., surveillance and reconstruction. We examined the subject matter of these messages and the women's purposes for writing about these issues with an emphasis on the subsequent socioemotional and practical details that went unaddressed in medical consultations leading up to the decision to undergo PM. We were also interested in learning more about how the women used the message board with these gaps in their preparedness, what sort of information and support they received from the message board and how they "gave back" to the message board regarding the issues surrounding prophylactic mastectomy. Such reciprocity in social support seems to be an important theme in these messages. We examined threads about prophylactic

mastectomies on the archived message boards during the period June 2000 – March 2004. In contrast to our past investigations, we decided to concentrate on three paradigmatic case studies, chosen because of their completeness and representation of three distinct courses of action. A manuscript has been completed and is undergoing final editing for submission. The abstract is

We present three comparative case studies of women with an extensive family history of breast/ovarian cancer who make different medical management choices. -- prophylactic mastectomy (PM) with reconstruction, PM without reconstruction, and surveillance. We view their early decision-making and choice of medical management as a single process bounded by a social context consisting of stages or a trajectory (Roth, 1962; Suchman 1965; Carroll and Johnson, 1990; Charmaz 1991); Thompson (1999); Folkman and Moskowitz, 2004; Henderson et al., 2006. These stages often demarcate transitions and decision-making points in medical care and behavior. We used qualitative analysis of chronological posts on the Facing Our Risk of Cancer Empowered (FORCE) archived message board in the early 2000s involving identification of themes in messages discussing PMs. We compiled dates and duration of the posts, and used close reading based on an inductive process involving coding and identification of recurring patterns, relationships and processes in the data, emphasizing the participants' own accounts of their phenomenological and social world. The women appeared to go through four linear sequential stages. The first stage is apprehension/information gathering and women appear to go back and forth between the two. The second stage is "taking the plunge" -- deciding upon, scheduling and undergoing a PM. The third stage is "healing/setbacks". This stage varies in length and difficulty depending on whether physical/psychological problems develop. The last phase we label "regeneration" when the women report that they are ready to get on with their lives. Women who post but who eventually decided on surveillance appear to truncate the process. As far as we know, no research has followed prospectively the progress of individual women from their initial decision to reduce their risk of developing breast/ovarian cancer to the final outcome of their choices.

5) The fifth issue we investigated concerns the attributions make about their cognitive and affective experiences following prophylactic oophorectomy (PO). Understanding attributions for changes is important, as these influence satisfaction with decisions to undergo PO as well decisions about symptom management. Liisa Hantsoo, a junior member of our team, presented data examining attributions of cognitive and affective changes among women who had undergone PO at the 2007 *Society of Behavioral Medicine* conference in a presentation entitled, *Women's Attributions of Mood and Cognitive Changes Following Prophylactic Oophorectomy*. Results indicated that women posted about as often concerning positive mood and cognition changes as negative changes, but were more likely to attribute changes to hormonal rather than nonhormonal causes. While women were about equally likely to attribute positive or negative changes to hormonal effects, negative experiences were more often attributed to loss of hormones than were positive experiences. These data suggest that women who experience negative changes following PO may consider utilizing contraindicated hormone replacement to obtain more positive outcomes. These data are currently being prepared in manuscript form.

The funding for the project has ended, but we continue to exploit the resources of it, including our past work for further research, particularly the downloaded files we have downloaded, documented, and archived. Our published work has generated others' interest in use of material downloaded from F.O.R.C.E.. However, after discussion with F.O.R.C.E., it was decided that to

ensure appropriate use and protection of the women using the chatroom, the files would be archived and password protected, with access determined on a case by case basis.

We remain interested in the use of more quantitative analytic methods to supplement our qualitative analyses. Importantly, we want to characterize quantitatively our qualitative impressions of the web community being structured around high user opinion leaders, women making posts around specific issues and then disappearing into the background, and a large pool of lurkers. Also we have obtained transcripts of online breast cancer support groups and are intending to make systematic comparisons and contrasts of the support processes that are evident in these groups versus F.O.R.C.E.. Finally, we have been negotiating with Jamie Pennebaker of the University of Texas to provide access to dissertation students who wish to undertake formal textual analyses of our F.O.R.C.E. data. These more linguistic analyses involve quantification and we will see if the results corroborate our qualitative analyses,

Key Research Accomplishments

- Demonstrated the unique unmet needs of women with HBOC across an extended decision-making process in terms of their lack of informational support, particularly concerning the felt experience they face in exercising their limited options for risk reduction, and emotional support.
- Identified inadequacies in the process of genetic counseling as typically experienced by these women in terms of a lack of an opportunity to discuss psychosocial and more deeply personal consequences of the decisions they face, as well as a limited access to counselors beyond initial consultations.
- Identified how HBOC women utilize specialty mental health services to obtain the emotional support they cannot readily obtain from genetic counselors, but with the distinct disadvantage that mental health providers are not educated about the medical or personal aspects of high risk status or of opting for particular risk reduction strategies.
- Identified a strong sense of stigma among women who opt for BPO or BM and isolation, despite the well established risk reduction achieved with these methods.
- Identified how F.O.R.C.E. website and associated web-based community address unmet needs of HBOC women in terms of informational and emotional support, particularly their needs for first hand “lived experience” vitally relevant to decision making. The F.O.R.C.E. is unmatched by professional resources in terms of immediate accessibility, mutuality of support processes, and advocacy and direct action.

Conclusions

Overall, HBOC women are profoundly affected by knowledge of their genetic status and actively seek medical information, experiential information, and emotional support from members of the FORCE community that is often not available elsewhere.. These women face potentially life altering decisions concerning risk management strategies and struggle to balance risk reduction and quality of life. The women who posted to the message boards were knowledgeable and proactive in their efforts to take control of their own health. They experienced feelings of loss, as well as a changing sense of themselves as women during the adjustment to risk reducing prophylactic surgeries, and repeatedly expressed concern over the inadequacy of current research to address the issues most relevant to their health and quality of

life. Specifically, studies that report the effects of HRT on menopausal women tend to focus on natural or surgical menopause in older women, but do not include younger high-risk women who have undergone surgical menopause for reduction of breast cancer risk. Nor do such studies explore the effects of alternate forms of HRT, including individualized bio-identical formulations. Controlled studies examining the impact of multiple forms of HRT on breast cancer risk in BRCA+ women following PO are warranted. Overall, there are substantial gaps in the preparation of these women for the experiences associated with decision making concerning risk management and the consequences of these decisions.

Our results can be used to provide some concrete clinical and policy recommendations for improving the HBOC women's preparation and subsequent adaptation to their status, particularly among women who do not have the benefit of the unique resources of F.O.R.C.E. Namely, the content of counseling sessions should be expanded to include medical and psychosocial information needed in the longer term adaptation process. DVDs and other interactive media could be a way of satisfying women's need for more personal presentation of the "felt experience" of living with risk reduction options. Counseling should be more accessible, with scheduled follow up or booster sessions. Consideration should be given to integration of mental health professionals into the decision making context of HBOC, but with greater attention to these professionals being better informed. Results of our project could be used as the basis for developing continuing educational materials for mental health professionals interested in working collaboratively with genetic counselors and HBOC women. Finally, *British Medical Journal* has previously identified F.O.R.C.E. as the best website of its kind in the world for addressing the needs of HBOC women. Our results can be used to generate informational material for professionals in a position to refer HBOC to the website and to evaluate further its appropriateness.

Reportable Outcomes

Completed Presentations:

Coyne, J.C., (September, 2005). *So genetic testing is not traumatic, now what?* Invited Lecture: Grand rounds, Department of Medical Genetics, University of St. Andrews School of Medicine.

Hantsoo, L.V., Coyne, J.C., Friedman, S., & Palmer, S.C. (2007). *Women's Attributions of Mood and Cognitive Changes Following Prophylactic Oophorectomy*. Poster presented at the Society of Behavioral Medicine Annual Meeting, Washington D.C.

Hantsoo, L., Coyne, J.C., Friedman, S., Palmer, S.C. "Women's Attributions of Mood and Cognitive Changes Following Prophylactic Oophorectomy." Congressionally Directed Medical Research Programs, Breast Cancer Research Program Annual Meeting June 25–28, 2008, Baltimore, Maryland.

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. (June, 2005). *Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board*. Paper presented at the 9th International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer, Philadelphia.

Kenen, R. H. *FORCE as a Web Based Support Group and Information Source*. Presented at Hereditary Breast/Ovarian Cancer Family support group at the Royal Marsden NHS Trust, October, 2005.

Palmer, S. C, Shapiro, P. J., Friedman, S., Coyne, J. C. (June 2005). *Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer*. Poster presented at the Department of Defense Era of Hope Conference, Philadelphia.

Shapiro, P. J., Kenen, R. H., Hantsoo, L., & Coyne, J.C. (2005). *Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board*. Paper presented at the 2006 Society of Behavioral Medicine Annual Meeting.

Publications

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. Peer-support in coping with medical uncertainty: discussion of oophorectomy and hormone replacement therapy on a web-based message board. *PsychoOncology*. 16: 763–771, 2007.

Kenen, R.H. Shapiro, P.J., Hantsoo, L., Friedman, S., & Coyne, J.C.: “*BRCA1/2* women renegotiating a post-prophylactic mastectomy identity: Self-image and self-disclosure.” *Journal of Genetic Counseling*, 16 (6): 789-798, 2007.

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Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. Peer-support in coping with medical uncertainty: discussion of oophorectomy and hormone replacement therapy on a web-based message board. *PsychoOncology*. 16: 763–771, 2007.

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List of personnel who received salary support during grant period

James C. Coyne, Liisa Hantsoo, Regina Kenen, Laura J. Hanisch, Pamela Shapiro

Appendices

1. Published Manuscripts

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. Peer-support in coping with medical uncertainty: discussion of oophorectomy and hormone replacement therapy on a web-based message board. *PsychoOncology*. 16: 763–771, 2007.

Kenen, R.H. Shapiro, P.J., Hantsoo, L., Friedman, S., & Coyne, J.C.: “*BRCA1/2* women renegotiating a post-prophylactic mastectomy identity: Self-image and self-disclosure.” *Journal of Genetic Counseling*, 16 (6): 789-798, 2007.

Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board

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Abstract

The Facing Our Risk of Cancer Empowered (FORCE) website is devoted to women at risk for hereditary breast and ovarian cancers (HBOC). To understand the unique health concerns and emotional support needs of these women, we examined threads on the FORCE archived message boards with relevance to the broader HBOC community. We report on a thread discussing the controversial decision to use hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. Twenty-nine women posted 177 messages over 7 months. Two main groups of women posted: (1) Women who were BRCA+, had completed PO, and were debating or adjusting their HRT options in terms of optimizing both quality and quantity of life. (2) Women who were BRCA+, were contemplating PO, but wanted to better understand the potential physical and psychological consequences of surgical menopause before deciding. Frustrated by physicians' lack of knowledge and contradictory media articles about the long-term consequences of HRT in BRCA+ women, they sought resources, emotional support and specific experiential knowledge from each other and generated a unique sense of community and a high level of trust. Copyright © 2007 John Wiley & Sons, Ltd.

Keywords: internet; prophylactic surgery; BRCA; hereditary risk of cancer; quality of life

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Introduction

Approximately 5–10% of the estimated 213 000 women who will be diagnosed with breast cancer and the 20 000 who will be diagnosed with ovarian cancer in 2006 [1] will have an identifiable genetic mutation predisposing them to hereditary breast and ovarian cancers (HBOC). For women carrying a BRCA1/2 mutation, the lifetime risk of breast cancer is approximately 50–85% and the risk of ovarian cancer is approximately 15–40% [2,3]. Although there are a number of strategies for managing HBOC risk, including surveillance, chemoprevention, and prophylactic surgeries [1,4], each can have negative consequences for both immediate and long-term health and quality of life. Thus, women seeking to reduce their cancer risk face complex medical decisions. Emerging data describing the risk-reduction benefits of various measures can provide a basis for decision-making [5–9]. Unfortunately, many women in the community do not have access to specialized genetic services where such information can be individual-

ized and discussed in educational and counseling sessions. For these women, the internet can provide a lifeline to support and information.

Although there are a number of internet sites for women with breast or ovarian cancer, *Facing Our Risk of Cancer Empowered* (FORCE) is the only website exclusively serving the needs of women at high-risk for HBOC. FORCE receives approximately 1 000 000 hits per month from all over the world and has been described as the best site in the world for HBOC patients to be directed by their physicians [10]. The website provides links to informational resources, a 24 hour message board, and a chat-group. Since FORCE was started in 1999, more than 50 000 messages have been posted. The archives include posts covering a wide range of HBOC related issues from the initial decisions to undergo genetic testing to discussions of the long-term physical and quality of life consequences of various risk management and preventive strategies.

As participation on the FORCE message board likely reflects unmet needs, the limitations of community resources, and the ambiguity

surrounding appropriate medical care for high-risk women, these posts provide a unique opportunity to examine the difficulties high-risk women face as they strive to reduce their cancer risk and regain control over their lives. As part of an ongoing project to identify and understand the needs of the high-risk community, we examined emergent themes in the content of women's communications on the FORCE message boards and identified several concrete problematic situations. One of the most prominent issues centered on the decision to use hormone replacement therapy (HRT) following prophylactic oophorectomy (PO).

Many women with BRCA mutations choose prophylactic surgeries—removal of both breasts and/or removal of the ovaries because these procedures are associated with the greatest risk reduction [11,12]. PO confers up to a 50% reduction in risk for breast cancer and up to a 95% reduction in risk for ovarian cancer among BRCA positive women [7,9]. However, these risk reduction benefits are not without cost and the physical and emotional sequelae of PO, particularly for younger women, can be substantial [13]. Surgically induced menopause hastens many of the changes associated with gradual aging including vaginal atrophy, reduced libido, accelerated bone loss, and increased LDL cholesterol [14,15]. To complicate matters, HRT traditionally used to reduce the negative impact of early menopause may be contraindicated in women with BRCA mutations. Research on the use of HRT in mutation carriers is in its early stages and the medical community cannot provide definitive evidence about the possible value or harm of HRT for this population.

Faced with life altering decisions in an atmosphere of medical uncertainty, the women in the FORCE high-risk community turn to each other for information and support. In this paper, we focus on their psychosocial and physical concerns surrounding the choice of PO for risk-reduction and the processes involved in the decision to use HRT for management of menopausal symptoms and related health issues.

Method

Selection of thread

This study was approved by the University of Pennsylvania School of Medicine. In order to protect the privacy of women currently posting on the FORCE message boards, only the message board archives were examined. These archives are password protected and access is provided by the executive director on a case by case basis. We used the quantity of messages and duration of the ongoing conversation to identify threads with

significant interest to the FORCE community. The thread titled, *Impacts of Surgical Menopause and Hormone Replacement Therapy Usage (PO-HRT)* was the most active of all individual threads, consisting of 177 messages posted in a continuing conversation over a 7 month period during 2001–2002. In addition, text searches of the entire archive were performed for posts including key words hormone replacement, estrogen replacement, HRT, and ERT. An additional 708 noncontiguous posts dealing with the same issue appeared throughout the 5 years of archived posts, but these did not occur in the concentration and duration of the selected thread. Thorough reading of these related posts insured that the selected thread was representative of the shared concerns, uncertainty, and support surrounding the issue of HRT following PO on the FORCE message boards, and allowed examination of the issues over time within the context of emerging medical literature.

Participants

Twenty-nine women contributed to this thread between August 2001 and February 2002. We do not have data concerning 'lurkers' or visitors to the website who may have viewed the thread without posting. For the purposes of this report, the screen names of individual posters were replaced by pseudonyms to assure anonymity.

Analyses

Analyses were conducted in several stages using a mixed method design combining quantitative and qualitative approaches and both inductive and deductive reasoning. Applying a similar process to that used in developing a semi-structured interview guide or moderator's focus group guide, broad topics of interest were first identified by review of the existing literature and informed by our experiences working with the high-risk population. Specifically, the areas of communal problem-solving, medical uncertainty, value or perspective discrepancy with professionals, and processes of social and emotional peer-support were selected as themes for investigation. Quantitative analyses involved counting women who posted at various times and in various categories, and the number and content of posts dealing with specific themes.

To ensure the integrity of the qualitative aspect of this study, a qualitative sociologist who was not involved in the genesis of this project and initial identification of themes analyzed the HRT and oophorectomy thread using an inductive process involving coding and identification of recurring patterns, relationships and processes in the data, emphasizing the participants' own accounts of their phenomenological and social world [16–18]. A conceptual account based on the women's postings

on the message board was developed, emphasizing the meaning in human action, and helping to identify various elements in the thread under investigation which might otherwise remain hidden [19]. To ensure that all major themes were identified, we used close reading and hand coding of the data as well as parallel coding by a second investigator using N*Vivo by QSR software, a qualitative analysis software program.

We then examined posts for evidence of *a priori* themes, integrated these with new themes derived from the posts, and then revised our initial tentative ideas about these issues in light of the content revealed by qualitative analyses. Posts were reexamined in an iterative fashion, adding explanatory detail and support for both revised *a priori* themes and the themes generated by the qualitative analysis. The latter dealt primarily with the women's use of the new social space provided by the FORCE internet support group, and the processes of developing trust and social community [20].

Results

Poster characteristics

Of the 29 women participating in this thread, 17 posted more than three messages; five posted 10 or more messages, nine women only posted once, and one woman dominated with almost one quarter of the messages posted under three screen names. Two main groups of women posted: (1) women who were BRCA+, had completed PO, and were debating or adjusting their HRT options in terms of optimizing both quality and quantity of life, and (2) women who were BRCA+, were contemplating PO, but wanted to better understand the potential physical and psychological consequences of surgical menopause before deciding. The majority of women were in their 30s; some were breast cancer survivors and others were *previvors*—survivors of a predisposition to breast and ovarian cancers.

Content and themes

Overview

This thread represented a nexus of uncertainties that required near-term decisions with long-term consequences in an area marked by lack of consensus among physicians. The participating women were generally young, felt alone and vulnerable, and wanted to gain some control over their lives. Frustrated by physicians' lack of knowledge about the long-term consequences of HRT in BRCA+ women and the contradictory information presented in media articles, they sought resources, emotional support and specific experiential knowledge from each other. These

women were concerned about the increased breast cancer risk associated with HRT, that they might essentially be undoing the benefits derived from PO by taking HRT, and that the immediate and long-term quality of their lives would be compromised without it.

While the provision of emotional support was a key element, the women were also eager to learn the latest scientific and medical data. Many of the posts cited information from recent pertinent articles in high prestige professional journals accompanied by informed critiques which generated further discussion. They also shared contact information for various medical centers around the country, provided telephone numbers for diverse organizations such as the National Women's Institute and The Women's International Pharmacy, and directed women to other websites that provided relevant information.

Building a social community; reducing a sense of isolation

The FORCE community consists of women in a similar predicament whose common breast/ovarian cancer risk outweighs their differences. Outside of members of their families, they did not meet many women who were BRCA+ in their every day life. Even though some of the women reported being surrounded by supportive relatives, friends and doctors, they still felt alone at times and wanted to reach out to someone who really understood them.

We may have great doctors, we may have supportive friends and family members—but unless those folks have experienced breast or ovarian cancer, they can't understand what we have gone through, what we face, and what we fear. That is why FORCE is so important. . . it allows us to share with other women who really understand. You are not alone in this. Take care! Hugs, Francine
I really appreciate all of you being out there. My husband is still a little in denial and doesn't really proactively talk about this situation. I'm a little in denial too, so I can't blame him, but oh, do I feel lonely and alone in this sometimes. Deidre

The messages on this thread included several different substantive topics, asked and answered questions, spoke of tears and anguish, but these were mixed with words of optimism and humor. Humor was a hallmark of this thread. It lifted the women's spirits and provided a source of bonding.

Edith, Nora & Tessa- Thanks for all of the wonderful giggles. Nora, were you tickling my spirit on your walk? I couldn't stop giggling for some reason and I have a feeling you were behind it. Okay. . .let me ask you all a couple of questions. HRT makes one lose weight? *looks for silver lining* Also, how is your sex drive? That isn't a proposition. . . I'm interested for myself. . .and DH. Tessa. . .I bet you are gorgeous bald! Have you thought about keeping it shaved? I kept my head shaved a half year after chemo and loved it. Candi

Beyond its role in providing social and emotional support for women who felt isolated, the FORCE community also played another pivotal role. It functioned as a source of information and a means for communal problem solving. The following message by Erin concisely represents many of the themes in this thread. Erin raises the two crucial issues that the women posting on the thread are concerned about, PO and the use of HRT. She wants to learn what another oncologist treating BRCA+ women says about it. Here she is gathering medical information, but is also asking about personal experiences. In one paragraph, she welcomes a poster back and reaffirms her importance to the group. She does not use 'I' when talking about missing her, but 'we' indicating that she feels connected to and able to speak for others. She signs the posting 'your HRT sister' which highlights the fictive kin (nonaffinal or blood relations that are considered part of the family) aspect of the thread.

Dear Nora, It's great to have you back!! We missed you! I know this issue of HRT is so complex. Here we are doing the pm/ooph trying to save our lives, but then we still need to make this really important decision to take or not to take HRT. I will be really interested to hear what your oncologist has to say tomorrow. Are you currently having any side affects from not taking HRT? your HRT sister, Erin

Deidre's post is also typical of many of the messages. She shifts back and forth between her quest for information and her personal feelings and opinions. She is at the beginning of her decision-making journey considering the future consequences of her choice of PO as a risk reduction strategy.

I believe I will have the ooph this year. I've become extremely paranoid that my cells are becoming cancerous as I speak. Where did you get informed about the post-op effect, HRT, hists, etc.? I feel like I really need this doctor to spend a long time explaining everything, but I know most give you the rush after about 15 minutes. Why do most of you have an ooph AND a hist, not to mention the PM? I always thought the detection for breast was so good that I'd catch it and cure it if it happened. Also heard that the ooph lowers risk of bc. Deidre

Sharing a dilemma; making a choice

The search for an HRT regime that would not increase their breast/ovarian cancer risk was fueled by women who were dissatisfied with how they felt and looked. Reduced energy level, a certain mental 'fuzziness', lack of libido, changes in skin, and weight gain were the most prevalent unwelcome changes mentioned in their messages. Their angst may be due in part to their young age, as most of these women were in their 30s or early 40s, or had undergone PO while in that age range. As a consequence, reactions to their abrupt surgical

menopause may be stronger and symptoms perceived more negatively than those of older women who experience the more gradual changes associated with natural menopause. Nora's complaints about the negative side effects of her PO without HRT were typical.

I'm two years' post TAH/BSO [total abdominal hysterectomy with bilateral removal of fallopian tubes and ovaries] and am dissatisfied with the dramatic changes to my energy level, memory, libido, skin, and weight. This dissatisfaction stems directly from the surgical-menopause....I'm going to take HRT (a minuscule amount that is as close as possible to the natural versions: 'individualized bio-identical hormone replacement'. My strongly opposed, otherwise highly supportive physicians, don't know this yet. And, it was actually another reason for my second breast removal—to allow for that additional slight edge of HRT. Sick but true. Nora

While Nora made her choices after a great deal of thoughtful investigation, she like many of the women posting on this thread, expressed distress about the loss of their fertility and how PO affected their entire bodies. Nora writes poignantly about mourning both the loss of her breasts and her fertility. She is upset that others have downplayed the 'invisible' loss of her ovaries—the primary sex characteristic responsible for feminization of the body, reproduction, and hormonal regulation—but empathized with the loss of her breasts, which are less crucial to the essence of being a woman. Her experiences with both friends and physicians suggest that external appearance, indeed conformity to societal norms of what features define the female body, supersedes what is necessary for her health and well-being.

you can't 'see' reproductive organs but the whole world can 'see' boobs...With both medical people and friends there's been almost nonchalance about my TAH/BSO and so much fuss about the loss of my breasts.... Don't get me wrong in that I really miss mine. Perhaps I'm still perturbed with a general societal value that was placed on my breasts instead of my unborns. Perhaps I'm not done mourning the latter. Nora

These women were attempting to deal with the aftermath of their POs and represented approximately half of those posting on this thread. The remaining women were still considering this option. Some had scheduled their surgery, but were afraid of both the physical and emotional after effects. They had heard all sorts of stories and wanted to learn about other women's experiences to get a 'reality check'. Reading about the unpleasant side effects upset some of the women who were contemplating PO.

Diane wrote about how frightened she was of the unknown. She worried that an oophorectomy would affect her personality, leaving her with the 'flatness' others described, and how that would

affect her marriage. She was concerned primarily with the existential question of who she was now and who she might become.

Is it just me or does everything I hear sounds worse and worse for the ooph? I am just so scared of the unknown of how I will be after. I am known for my passion. When I feel passionate about something, watch out. To hear that I might not be this way after is pretty scary. How do you cope with all of this? How am I going to go in and do this knowing my personality might be different.... Sorry to be thinking out loud but if I will be a different person, will it be worth it? Diane

Others felt overwhelmed by the enormity of the decision they faced. Although Candi had hoped the discussion would clarify her options and simplify decision making, this thread served to highlight the complexity of the issues and evoked the sense that it was a *no win* situation.

okay... It's been an hour since I've read this string and I'm still crying. I HATE MAKING THE CHOICE BETWEEN TWO EVILS!!!! I agree with EVERYONE and am ripped apart. I have to do everything I can to live as long as possible for my daughter, husband, and myself. Yet I know all of the problems I have had with my many surgeries and KNOW that I will be terribly messed up with no guarantee they will figure out the right combo of drugs for me to fix the 'side effects.' I hate that I have to live this way. Candi

These women apparently felt safe enough on the FORCE message board to express their deepest emotions whether they dealt with fear of the unknown, worry about changes in their personalities, being distraught about having to choose between 'two evils' or mourning the loss of their female body parts. Not only did they feel compelled to make decisions they believed no woman should have to make, but to compound their distress, they lived in a society that placed a very high premium on breasts while undervaluing the severe physical and psychological implications of a PO.

Medical uncertainty and value discrepancy

In 2001–2002, during the seven month period when this thread was active, physicians could not agree on whether women who were BRCA+ and opted for a PO should use HRT [21,22]. The available clinical epidemiological data from older and non-BRCA+ women was of limited relevance, and offered little in the way of guidance for decisions about HRT. This was reflected in the conversations the women reported having with their doctors and in reaction to their searches for a definitive medical answer. Most of the women, though not all, were posting on this thread because they wanted to begin receiving some form of HRT.

This is one area that I am trying to decide about too. My breast surgeon says 'no' and gyn says 'yes' to HRT

(Haven't had my surgeries yet, am planning for early January, so I have some time to research this HRT dilemma) Would also love to hear from the group on this subject too. Erin

I wish there were specialists in this area of knowledge. Right now, it seems to be such an unknown factor as to what to do! Clear as mud! Darlene

There also seemed to be a discrepancy between the values of the physicians and the values of some of the women.

My doc is very cavalier about the emotional side of this, says I don't need testosterone because libido is 'all in one's head,' but I may decide he's wrong if I become emotionally numb. Deidre

According to their messages, some of the women's doctors, particularly their oncologists, did not want them to take HRT until more research had been conducted. The women reported their sense that their oncologists were more interested in keeping them alive than they were concerned about the quality of their lives. The women, however, were interested in both quality and quantity of life.

Here again is where things are soooooo confusing. My oncologists don't want me on anything that even closely resembles estrogen. They don't want me on testosterone as a breast cancer survivor (different situation from all you pre-vivors out there). I was told that there aren't any conclusive studies on safety in bc survivors (again, not talking about bc pre-vivors) Tina

I know oncologists are against hormones. However, sometimes I feel they may be more interested in survival than in quality of life. I wish there were more definitive answers out there. It seems horribly cruel to deprive us of hormones that keep 'normal' women healthy. They need to figure out why estrogen becomes the enemy of some! Darlene

Trust your body; trust yourself

Throughout the message boards, posts appeared emphasizing that every woman was unique and that any decision was 'right', if it was right for that individual. These posts, along with those presenting individualistic experiential perspectives on surgical menopause and HRT, provided an ambience of acceptance and safety, allowing women to be more open about their feelings and share very personal experiences, even when these did not fit the general pattern. This freedom to be 'oneself' also fostered the development of a social community.

The post by 'Anonymous,' illustrates this with a large dollop of humor. She reminds the women that their own menopause experiences will not necessarily conform to the models they have read about in the media or research literature. Her message echoes the theme 'trust your body, trust yourself'.

Dear all, My two cents... As a long time sufferer of hormone hell (pre-menopause) I totally, totally get the subtleties that hormonal differences can create... When hormones go awry the way you feel things can feel blunted... I always likened it to what I imagined wearing a condom felt like... except it was lining my insides and not my outsides. That being said, I can tell you that it's been 1.5 years since chemo fried my ovaries and 6 months since those little falafel balls were taken out. I actually feel better than I did for much of my 'healthy' years... you shouldn't have any preconceived notions about what life without HRT is... I think we get wrapped up in what our research and the media tells us it should be. All of your reactions and symptoms are valid, but they are personal to you. Over and out. Anonymous

Edith, who had suffered from what sounds like premenstrual syndrome (PMS) most of her adult life, sends a similar message challenging the universality of post oophorectomy difficulties. She exults in her post-oophorectomy existence and writes about how much better she looks and feels taking HRT than she did before. She answers a message from a distraught poster, providing comfort along with the specifics of her HRT use.

Dear Candi, I have never looked or felt better in my life since my ooph and pm... I am MADLY IN LOVE with not having a period, and figure I get one week per month minimally of not being achy, weeping, greasy, ugly and a general mess. I am on natural hormone crèmes compounded by a lab and prescribed by an internist. My ca123 and ca27/29 are VERY LOW and my estrogen level is on the low side of normal. I am also thinner and have a flatter tummy than at any other time in my life. Soooooooooooooooooooooo, so much for all the post ooph difficulties. They are not universal, so try not to despair too much. Happy Holidays, Edith

In sharing detailed experiential information about the outcomes of their personal HRT decisions, posters like Anonymous and Edith empower women who are still in early stages of decision making to explore individualized options to achieve personal well-being. In the following quote, Trixie thanks Edith for previous useful advice; in essence, each woman was passing the torch by sharing the details of her own successful natural HRT regimen to others.

Edith and others, I have been struggling with the hormone issue since my hyst/ooph [hysterectomy/oophorectomy] a year ago. I had decided on ERT [Estrogen Replacement Therapy]... But, I hadn't been able to get it right—and was working with a dr. that thought I was an equation. Edith had advised me to check out the natural hormone months and months ago... I am now on natural progesterone, natural estrogen (triest), and a little testosterone, and feeling much better. I haven't spoken to the dr yet about it, but, the books seem to suggest that I can wean off the estrogen over the next few months, stay on the progesterone, and probably still feel good... A belated thanks to Edith. Best regards, Trixie

Continuing PO/HRT Discussion on archived message board

Collective wisdom and reciprocity

Within six weeks of the final post on the *Impacts of Surgical Menopause and Hormone Replacement Therapy Usage* (PO-HRT) thread, the topic surfaced again and then appeared periodically in the archives until 2004. Both the quantity and duration of these subsequent threads were considerably less than the PO-HRT thread, with threads lasting between 1 and 9 days with a maximum of 30 posts. Fourteen of the original 29 women who participated in the PO-HRT thread posted on the topic during this period to share the information they had gathered previously, describe their experiences with PO and HRT, and offer support. They were reciprocating what FORCE sisters had given to them when they needed guidance and encouragement. Rather than reiterate the content of the PO-HRT thread, links to the archived thread were provided so that readers might view the content in its entirety. In this way, the thread became part of the collective wisdom of the FORCE sisterhood—a casebook of concerns, symptoms, and solutions occurring under conditions of medical uncertainty.

More information; more confusion

In July of 2002, approximately 5 months after the PO-HRT thread ended, a press release was posted on the FORCE message board announcing that the estrogen plus progestin arm of the Women's Health Initiative (WHI) clinical trials was closed due to the increased risk of invasive breast cancer, coronary heart disease, stroke, and pulmonary embolism in women taking estrogen plus progestin compared to those taking placebo. Three women involved in the PO-HRT thread participated in this thread, reiterating their concerns about QOL versus long-term health, and pondering the relevance of this information to their unique situations.

Kriz expressed anger and frustration at the news, aptly summing up the current limitations of medical knowledge and the difficulties that remain ahead for high-risk women facing decisions about PO and HRT.

I went a year with no HRT post ooph and watched my bone density go down and my cholesterol go up, my libido go away, my hair thin and so on. Now, after being on HRT for a year or so, I get to worry about cardiovascular disease and strokes and blood clots... And, I'm really wondering if there's a difference between medroxyprogesterone acetate and natural micronized progesterone (Prometrium) as I'm taking the micronized progesterone. But how long will it take for any studies on that to be done and reported on? Hmmmph!... Anyway, not sure what the point to my post is - maybe that I'm angry and I just need to vent! It's been said so many times before - there just are no easy answers regarding this.

Discussion

The objectives of this study were threefold; first, to discover and present high-risk women's psychosocial and physical concerns regarding surgically induced menopause; second, to clarify the processes involved in the decision to use or not use HRT, and third, to understand how the women use and benefit from an internet support group message board.

The specific findings need to be interpreted within the larger context of how individuals perceive risk and handle uncertainty—a complex and subjective process [23]. Women from HBOC families face a plethora of uncertainties—the uncertainty as to whether, or when, they will develop breast or ovarian cancer, as well as uncertainty surrounding the efficacy and risks associated with options. The main focus of the PO and HRT thread was the attempt by these women to take optimal steps toward reducing their high-risk for developing breast and/or ovarian cancer while minimizing the negative side-effects of their risk reduction strategy. Their concerns centered on the specific physical and emotional changes associated with menopause, particularly the immediate symptom distress following PO, but also the long-term impact of early menopause on physical health and quality of life.

Living with a high-risk of developing a life-threatening condition involves not only uncertainty but a considerable diminution of control over one's life—a highly esteemed value in western societies [24]. The women try to regain this control and resolve the decisional conflict they face by evaluating their options in terms of gain or loss. Resolution involves processing large amounts of new and difficult information and the message board serves as both a source of information and an evaluative resource. The women repeatedly emphasized that using the FORCE message board helped them re-exert control over their lives in order to avoid repeating the cancer histories of their relatives while maintaining good quality of life.

Although a recent analysis concluded that use of HRT after PO results in only a minor decrease in life expectancy (−0.17 to −0.34 years) if HRT is halted by age 50 [25], such an assessment was not available in the literature at the time of these postings, and data that are seemingly contradictory in their implications continue to accumulate [26]. The women participating in this thread had to decide whether to use HRT in the face of professionals' expressed concerns about initiating HRT before more clinical data were available or, in many cases, their physicians' outright rejection of the HRT following PO. The discrepancy between the women's preferences for at least low dose HRT and the professionals' reservations and resistance were seen as reflections of differences in the value placed on absolute risk reduction versus

quality of life. There was a definite sense that professionals minimized the implications of the women having to live with an abrupt surgical menopause, even though at the time HRT was routinely prescribed to unaffected women for relief of menopausal symptoms [27]. The perceived lack of empathy and unhelpfulness of medical professionals reinforced the women's feelings that their health predicament separated them from others. This sense of isolation bound them together on the FORCE website in an emergent community.

The women contributing to this thread built their own social structure by engaging in reciprocal and multi-participant conversations over time. They appeared to ignore the public nature of the web site and treated FORCE as their private, treasured and very personal social space. A crucial theme evident in their posts was the development of trust among FORCE sisters. Trust is among the core reasons why women find web based support groups so helpful. Our findings are consistent with recent web research that has shown that women highly value information and advice from other women with the same medical conditions and experiences, and trust the information they provide [20,28].

Moreover, the sense of trust and community engendered on this thread appeared to enable these women to make the unpleasant choices they faced with a degree of confidence they otherwise might not have felt on their own. These choices were then validated by multiple posts reinforcing the concept that what any individual woman finally decides is right for them. In this way, trust in the community translated to its individual members. The motto 'trust your body, trust yourself' is reiterated in different words in many posts.

The literature concerning the role of web-based health resources developed by consumers is limited but growing, and the thread we reviewed can be interpreted in light of this literature. First, the thread can be viewed in terms of how online communities develop a *collective intelligence* in the face of medical uncertainty [20]. The thematic strategies for doing so, *articles and article discussion, requests for advice and information, and sharing information* [29] were clearly evident in this thread. The women sought experiential information from other FORCE members, tracked down relevant scientific literature, consulted with experts, and shared both experiential and medical information about the specific physical and emotional changes and possible long term implications of early menopause on physical health and quality of life.

The present thread is also relevant to the concept of the *expert patient* and has broad relevance in terms of people developing the knowledge to maintain their health and manage illness, thereby having greater control over their lives [30]. Research suggests that women use the internet to circumvent professionals' control of access to

health information and its interpretation [31]. A growing controversy concerning the expert patient [32] revolves around whether it is possible for lay persons to actually renegotiate a more balanced relationship with medical professionals, rather than merely being burdened with responsibilities previously met by the health system. The women participating in this thread seem to fulfill the more empowering view of the expert patient by integrating personal and medical knowledge to renegotiate their individual relationships with medical professionals [33]. As Radin [20] reports, it is the 'mundane and profound exchanges, the poignant self-disclosures [and] the creative expression of solidarity' (p. 591) that develops the *thick trust* necessary to breach the health community's monopoly perspective on health information.

The FORCE web site provided a critical mass of women who faced the same daunting issues the opportunity to *talk* to each other in a primary group setting that they had created. This enabled them to share the process of making the decision to use low dosages of HRT on both cognitive and emotional levels. After individual decisions about prophylactic surgery and HRT were made, women tended to fade back into the FORCE community, although the thread they produced remains as a resource for subsequent women facing such decisions. In this way, their messages contributed to the construction of social norms for dealing with the impact of PO—a reference point for future generations.

We should be careful not to over generalize from this thread. These women are extraordinarily resourceful and at least some of them apparently already had exceptional access to both the medical literature and to high quality, responsive health care. The thread may have allowed them to spread these resources to others, but many high-risk women, likely the bulk of them in the community, will not find access to this thread and the website on which it is available, as approximately 39% of American women do not go online [34].

The present study has several other limitations inherent in the use of posts on a publicly accessible website as data [35]. The views expressed by individuals posting on this thread might not reflect the collective views of those who read the messages but did not post themselves. As was the case in this study, one individual can dominate a thread, and this may have created an ambiance that inhibited other participants from expressing differing views. Because it is difficult to verify the identity of people posting on the website and the same individual may submit messages under different pseudonyms, fewer women may have participated in this thread than was indicated by the number of screen names. However, this is likely to be minimal on the FORCE website, where many participants voluntarily register their email addresses.

Despite these limitations, the methodology used for this study has several strengths. The combined qualitative/quantitative data analytic strategy and extrapolation of themes from a Web-based message board improves on traditional focus groups and interviews by eliminating the constraints imposed by the presence of a researcher-observer and by facilitating sampling of a larger group over an extended period of time. This strategy allowed us to observe women's real-time descriptions of coping and problem solving, rather than asking for retrospective accounts. As well, the selection of this particular topic, PO and HRT, was determined by the frequency and duration of its discussion in the archives, and so reflects its relative importance among community members.

This paper presents the first findings from an ongoing study examining the self-identified issues of greatest concern to women at high-risk for HBOC who participate in the FORCE on-line community. To date, much of the existing psychosocial research involving the high-risk community has focused on the immediate emotional status and decision-making of women anticipating and receiving genetic testing [36,37]. We focused instead on the psychosocial and physical concerns of high-risk women as they negotiate difficult risk-management decisions surrounding the choice to undergo PO and/or to use HRT to reduce the negative impact of surgically induced menopause. Our findings highlight significant dissatisfaction with the medical community's sensitivity to these issues as well as frustration with the then current state of scientific knowledge regarding HRT. Efforts to address these issues should include clinical evaluation of the efficacy and safety of individualized bio-identical hormone alternatives for management of menopause in high-risk women, education of physicians in the community about the ongoing needs of high-risk women, and development of decisional aids to help women resolve the dilemmas and choices they face. Finally, as use of the internet for medical information continues to expand, it is important to consider the ways in which a web based support group can be integrated into a more holistic health care approach.

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Women with *BRCA1* or *BRCA2* Mutations Renegotiating a Post-Prophylactic Mastectomy Identity: Self-Image and Self-Disclosure

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Abstract The Facing Our Risk of Cancer Empowered (FORCE) website is devoted to women at risk for hereditary breast and ovarian cancers. One of the most frequently discussed topics on the archived messaged board has been prophylactic mastectomy (PM) for women with a *BRCA1/2* mutation. We reviewed the messages, over a 4 year period, of 21 high risk women and their “conversational” partners who originally posted on a thread about genetic testing, genetic counseling and family history. We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. The women sought emotional support, specific experiential knowledge and information from each other. They frequently found revealing their post PM status problematic because of possible negative reactions and adopted self-protective strategies of evasion and concealment outside of their web-based community. The FORCE message board was considered to be a safe place in which the women

could be truthful about their choices and feelings. Results are discussed in terms of Goffman’s concepts “stigma” and “disclosure” and Charmaz’s concepts “interruptions,” “intrusions” and a “dreaded future.”

Keywords Prophylactic mastectomy · Reconstruction · Stigma · Web-based support group · Self-image · Self-disclosure · Renegotiation of the self

Introduction

Women carrying a *BRCA1/2* mutation, face an approximately 50–85% lifetime risk of breast cancer and a 15–40% risk of ovarian cancer (Ford et al. 1998; Brose et al. 2002; Altaia et al. 2003; Antoniou et al. 2003; Suthers 2007). Although there are a number of strategies for managing hereditary breast and ovarian cancer (HBOC) risk, including surveillance, chemoprevention, and prophylactic surgeries (ACS 2006; National Comprehensive Cancer Network 2007), individuals concerned about their risk may find it difficult to choose an option. Data concerning the risks associated with *BRCA* mutations, as well the risk reduction associated with these various measures are emerging (DeMichele and Weber 2002; Grann et al. 2002; Rebbeck et al. 2002; van Roosmalen et al. 2002; Van Sprundel et al. 2005), but there are many pros and cons to the above mentioned choices.

Prophylactic mastectomies (PMs) are being suggested to very high risk women because the data indicates that the development of a first or contralateral breast cancer is reduced by approximately 90–95% with PM (Peralta et al. 2000; McDonnell et al. 2001; Gui et al. 2003; Harcourt et al. 2003). However, this is still considered to be a controversial procedure (Zakaria and Degnim 2007), and

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Bresser et al., in their 2006 article, refer to PM as a radical intervention.

Although overall satisfaction with bilateral or contralateral PM has been reported to be very high, fewer women were satisfied with the cosmetic outcome, and a minority expressed feelings that their femininity and body image were adversely affected (Hopwood et al. 2000; Lloyd et al. 2000; Frost et al. 2005; Bresser et al. 2006; Lostumbo et al. 2004). Bresser et al. (2006) suggest “that the absence of regrets despite the awareness of adverse consequences reflect that the urge to reduce anxiety, remain healthy, and survive supersedes any ambivalence regarding the possible negative outcomes of PM/breast reconstruction in the long term” (p. 1681).

Even though most of the women undergoing a PM reported that they were satisfied with their choice, some individuals in society consider an intervention such as a PM akin to mutilation (Press et al. 2005). Respondents in Lloyd et al.’s study of women who had experienced a PM (Lloyd et al. 2000) reported that common reactions from friends and relatives were those of “shock” and “horror” (p. 477). Therefore, women who choose PM need to be aware not only of the many physical problems that frequently occur after surgery, but of their own psychological reactions to the actual, or perceived, reactions from others. Historically, stigmas have been attached to radical surgery (Kelly 1992). Thus, those women choosing a PM are likely to find themselves experiencing tensions between their expectations for the PM and reconstruction (if they decide to reconstruct), possible stigma, and whether, or to whom, the PM experience is revealed. In this situation, women need understanding and informed friends to talk to and a safe place in which to express their feelings.

The beneficial aspect of women’s friendships has been well documented by others (Apter and Josselson 1998; Aday et al. 2006; Kroenke et al. 2006). *Facing Our Risk of Cancer Empowered (FORCE)*, a nonprofit organization and associated website, creates an environment in which women feel free to tend (nurture) and befriend each other at a time of stress (Taylor et al. 2000; Taylor 2002). It is considered to be a safe place for these women to discuss their feelings, decision-making and clinical management options.

There are many other breast cancer web based support groups that offer chat groups, message boards, and professional advice and support; research indicates that they tend to be very popular (Helft 2004; Rozmovits and Ziebland 2004). Some address women from minority groups (Fogel et al. 2003) and others, like *The Breast-Cancer Mailing List*, welcome posts from friends, family, and caregivers of women with breast/ovarian cancer. However, FORCE is the sole website specifically devoted to the community of women at risk for hereditary breast/

ovarian cancer. The majority, though by no means all, of the women who post on the message board have not yet developed cancer, come from a family with a history of HBOC, and have tested positive for a BRCA1/2 mutation. FORCE receives one million hits per month from all over the world and has been described as the best site for physicians to direct their patients (Richards 2001).

In this paper we examine one of the topics most frequently mentioned by women posting on the *FORCE* archived message boards—consideration of the physical, psychological, and social consequences of PM during the decision-making, recuperation and reconstruction process. We report on the women’s feelings of loss, perceived stigma, tension between disclosing and concealing, and their need to renegotiate their sense of self and relationships with others.

The Conceptual Framework

Individuals use different strategies to hide, disguise or divert attention from a condition that they believe might stigmatize them. Some women consider undergoing a PM and reconstructing their breasts to be such a stigmatizing condition. A *stigma* refers to a negatively evaluated condition or attribute that sets the person apart from “normal” individuals in society (Fortenberry et al. 2002). Goffman (1963) discusses two kinds of stigma—discredited and discreditable. Stigma that are immediately obvious are called “discredited stigma,” e.g., severe facial burns or quadriplegia. An individual with a discredited stigma needs to manage social relationships taking her stigmatizing condition into account. A “discreditable stigma” is a knowable one that is not immediately obvious, e.g., severe burns or scars that are hidden, or history of mental illness. In these cases, information about the condition needs to be managed so that it remains unknown.

In Goffman’s terms, a woman who undergoes a PM would have a discreditable stigma. She can hide the information from friends, relatives and possibly children, who do not see her without clothes. However, when having sexual relations, the discreditable stigma becomes known and therefore discredited. These terms do not indicate that a condition in itself devalues an individual, but that some members of society might view it that way.

Goffman (1963) discusses “passing” – keeping a stigma unknowable – and “covering” – withdrawing someone’s attention from a known stigma – to indicate how individuals deal with keeping a stigmatizing condition secret or more palatable. People make assumptions about what a normal individual ought to be, and a normal woman is expected to have breasts—not to be completely flat chested or have surgically constructed replacements. Goffman (1963) asserts that because of the great rewards bestowed

on those considered normal, almost all individuals will attempt to pass on some occasions and those who cannot or do not want to “pass” will usually “cover”.

We integrate these concepts with Charmaz’s (1991) concepts regarding the self and time. We discuss “interruptions”, “intrusions”, and the idea that the sense of self is rooted in time as well as in relationships. *Interruptions* are small and temporary disturbances of one’s life, while *intrusions* are more substantial disturbances that require time, accommodation and attention (Charmaz 1991). Time refers to the individual’s social construction of the past, present or future. Charmaz uses these concepts to help explain how everyday thoughts about behavior, presentations, and interactions, become problematic and have to be renegotiated after a person becomes chronically ill, disabled or severely scarred. While a PM is different because the PM/reconstruction process is undertaken by healthy women attempting to avoid developing breast cancer, the concepts of “interruptions” and “intrusions” and “dreaded future are applicable in the PM case as well.

We also investigate how women strategically use disclosure and concealment strategies to manage the representation of themselves following PM (Hilbert 1984; Druley et al. 1997). In these studies, the researchers found that there is frequently contradictory pressure for patients to share and to conceal information about their feelings pertaining to their illness. “Dilemmas of whether or not to disclose illness information, and when, how often, and how much to disclose are issues with which patients must continually grapple” (Druley et al. 1997, p. 512). This paper is concerned with similar issues and addresses the tension between the PM decision and women’s renegotiation of a post PM identity, particularly self-image and self-disclosure. Themes associated with the everyday lived experience of undergoing a PM and reconstruction are to be reported in a companion paper.

Methods

Sample

We selected 21 women who posted on a two part thread about genetic testing, genetic counseling and family history at the end of 2000 and beginning of 2001. We chose this thread as our initial starting point because the messages concerned genetic counseling, genetic testing and family history—crucial factors that initiate the decision-making process regarding clinical management choices, namely surveillance versus PM (Ray et al. 2005). We chose to follow the same women over time, rather than investigate a larger group of women at one specific time because we wanted to study the emotional complexity of the PM

experience and explore cognitive and emotional adjustment and reappraisal of PM decisions as women became further removed from the actual procedure.

We included these 21 women’s posts regarding PM and reconstruction that appeared on the message board during the period January 2000–March 2004, the last date the archived posts were available when we first initiated this project. They posted 1171 times on the PM topic. The women were partners in “conversations” on the message board, and thus their posts frequently were responses to other women’s comments. We included messages from “conversational partners,” who posted 328 times to the 21 women in our sample, in order to understand both ends of the conversations. All messages are retained verbatim, including spelling and grammatical errors. Four dots “....” are used when parts of the message have been deleted because of lack of space.

The women were mainly in their thirties and forties, and we can infer from their posts that they were predominantly middle class and fairly well educated. This is consistent with the overall profile of FORCE members who use the message boards.

There were 17 women who had not developed breast/ovarian cancer, referred to as *previvors* by the FORCE community, and 4 cancer survivors. One woman started posting as a previvor but later developed breast cancer and started to post again.

This study was approved by the University of Pennsylvania Institutional Research Board. Women signing on to the FORCE website were apprised that the website was public access and might also be used for research purposes. In order to protect the privacy of women currently posting on the FORCE message boards, we only reviewed password protected archived messages. Access to the archived material is provided by the executive director on a case by case basis. All posters were assigned pseudonyms which provided an extra layer of protection against identification of their FORCE screen names.

Design

We primarily relied upon qualitative analysis involving an initial identification of themes in the messages discussing PM using an inductive process involving coding and identification of recurring patterns, and relationships and processes in the data, emphasizing the participants’ own accounts of their phenomenological and social world (Pidgeon 1996; Strauss and Corbin 1994; Glaser and Strauss 1967). We developed a thematic account based on the women’s postings on the message board in order to identify various elements in the thread under investigation which might otherwise remain hidden and to emphasize the meaning in human action (Beeson 1997). Two of the

authors used close reading and hand coding of the data until consensus was reached and all major themes were identified. This approach does not assume that there is only one measure of reality that is objectively grounded (Mathieson and Stam 1995).

Results

Table 1 describes the characteristics of the posters and frequency of their postings. (See Table 1.) The women in this sample varied greatly in the number of messages they posted about PM, the number of different women they addressed or answered, and the length of time they posted. A few women were mainly lurkers—women who read messages but rarely contributed to the thread (Nonnecke et al. 2004). The majority of women began posting at the time they were deciding whether to continue surveillance or undergo PM and stopped when they had finished their post PM reconstruction. During the time they posted, they actively supported each other emotionally and with experiential information. A few of these women posted briefly at a later time when they had a question or something was troubling them. A couple of women continued to post for years. These women wrote about their dedication to FORCE and wanting to “return” the support they had received by offering their experiences to new FORCE

posters who were now grappling with prophylactic decisions (Kenen et al. 2007).

Tension Arising from BRCA Testing and Decision to Undergo PM; Psychosocial Aftermath

Self-Image and Interpersonal Relationships

The effect on self-image and interpersonal relationships frequently starts with a positive genetic test result (Kenen et al. 2004) and can go on for years, often pervading the woman's life while she remains undecided how she wants to clinically manage her BRCA+ status. This can, in some cases, be considered a mental intrusion similar to an illness intrusion requiring time, accommodation and attention (Charmaz 1991). The actual PM and reconstruction is experienced more as an illness interruption which is temporary and over when it has been satisfactorily completed (Charmaz 1991).

Goffman (1963) also writes about how taken for granted aspects of what was formerly considered to be part of a normal life are no longer taken for granted. Irena reflects about something as simple as a hug. Hugs, which were a major part of Irena's emotional expression, especially toward her children, became problematic and resulted in “bruising” as an unanticipated and uncomfortable side effect of her hard breasts. Hard reconstructed breasts were a common complaint by women on the message board.

Table 1 Characteristics of the Posters and Frequency of Their Postings

Pseudonym	Pre/Survivor	Dates	Length	# Posts
Caitlin	Survivor	11/00–3/04	3 y, 5 m cont.	184
Faye	Previvor	12/00	0 y, 1 m	6
Flo	Previvor	3/00	1 post	1
FR	Previvor	1/01–3/01	0 y, 3 m	8
Ilene	Previvor	6/02–10/02	0 y, 2 m	2
Indigo	Previvor	5/00–7/00; 8/03–10/03	2 y, 3 m; 0 y, 3 m	55
Irena	Previvor	8/00–3/04	3 y, 8 m	202
Katya	Survivor	7/00–12/00; 1/04–3/04	0 y, 6 m; 0 y, 3 m	14
Liza	Previvor	7/00–6/01; 10/02	1 y, 0 m; 1 post	35
Lonnie Q	Survivor	12/00; 5/01	0 y, 1 m; 1 post	3
Lou	Previvor	5/00–3/01	0 y, 11 m	24
Mariella	Previvor	11/00–4/01	0 y, 6 m	89
Parcy	Previvor	11/00–4/02	1 y, 6 m	26
RA	Previvor	9/00–1/02; 6/03–8/03	1 y, 5 m; 0 y, 2 m	51
Randi	Previvor	1/00–3/01; 9/02; 11/02	1 y, 3 m; 1 m; 1 m	65
Rina	Previvor	1/01–7/01	0 y, 7 m	7
RY	Previvor	8/00–10/01; 9/02; 2/03	1 y, 3 m; 1 post; 1 post	97
Sally	Previvor	8/00–1/02; 5/03; 9/03; 3/04	1 y, 6 m; 0 y, 1 m; 2 posts; 1	116
Ursula	Survivor	6/00–3/02	2 y, 9 m	81
Wanda	Previvor	11/00–5/01; 10/03	0 y, 7 m; 2 posts	12
Zoe	Previvor	4/00–3/02; 1/03	1 y, 11 m; 1 post	93

....I ended up switching to silicone a year later and have been very happy. They are soft and I can lay on my stomach no problem. My entire family is happier and no longer has “boob bruising” on their bodies after long hugs. Seriously, they got in the way of good hugs.

Irena

Feeling Different—Feeling Loss of Natural Breasts

The fear of loss of femininity, sexual attraction and loss of sexual pleasure were in the minds of many of the women. Liza feared her own reaction to her loss of breasts. Lee J feared her husband’s reaction. Both women expressed anxiety about the physical results of their PM decision.

Just wanted to let everyone know that I am counting down the days until my PM.... Getting a bit nervous. Not so much for the surgery (although that’s a bit scary) but for my reaction to loss of breasts. Reality, and my reaction to it, does frighten me! I will keep everyone posted once I am up and around. Thanks,

Liza

Irena....I am still extremely anxious about the surgery. I also fear how my husband (of only 1 year) will react post surgery....How is he going to react when he sees my battered body?....

Lee J

Perception of Self/Other Stigma

Concealing Through the Use of Clothing When a person perceives a stigma attached to a body characteristic that can be hidden, she can choose to reveal it or conceal it. This can be done verbally and through the use of clothing. In Caitlin’s case, it seems more of a feeling of self-stigma rather than a stigma from a significant other. Even though Caitlin says she does not dwell on how her new breasts look, 3 years after her reconstruction she admits that she is still uncomfortable in the nude or “reveal” state even though her husband feels comfortable with her reconstructed breasts. The merest wisp of a cover such as a camisole top shifts her to a happier “conceal” state.

I am less self conscious in a tank top or camisole when I am with my husband intimately, though he doesn’t mind them. My pm was 3 years ago. I do love how they look in clothes which is an upside. I am self conscious naked, but don’t dwell on it, since I don’t feel my prior bc and positive braca status left me with any alternatives.

Caitlin

However, it is how she looks in clothing, a more total concealer that makes her feel very good about herself. While Caitlin feels a tension between reveal and conceal, she actually feels little tension between the PM decision and its aftermath. She felt that her previous breast cancer and positive BRCA status did not leave her an alternative to PM.

Carin and Zoe were each pleased with their reconstructed breasts. Carin was comfortable revealing her body to her husband and was delighted to hear that he found her new breasts beautiful. The women frequently wrote about their need to feel sexually attractive.

Irena....I had my implants exchanged for silicone on December 29, 2000. So far they are great. I can’t feel the implant inside my body, they feel like real breasts, no sloshing and they look great! Even my DH told me that my “new breasts” are beautiful....

Carin

Zoe normalized her new breasts by saying that in clothes nobody could ever detect they were not real and that her plastic surgeon brought up the suggestion of a “natural droop” to emulate real breasts. Her reference to her feelings that nobody could tell they were not real indicates that Zoe was probably a “concealer”, with strangers at least.

Dear Babs, I LOVE my implants....I can say my only “complaint” (although I think that word is far too strong a word to describe my feeling here) is that they are very firm. Not bad or uncomfortable, just not as soft and squishy as my old breasts used to be. Otherwise, I think they look great! The shape is good, and in clothes no one would ever detect that they weren’t real...

Zoe

Lonnie Q was one of the few posters who decided not to reconstruct. In her case, living in Hawaii – where the muumuu and cool, comfortable clothing that concealed all types of body differences were the norm – made the decision not to have reconstruction more palatable. In addition, her husband has been supportive of her decision. The combination of being able to dress in “normal” clothing with being able to reveal her unreconstructed breasts to her husband appear to have helped Lonnie avoid feeling any self stigma or stigma from others.

....i am quite happy with not having the reconstruction and being flat chested. my husband has been very supportive with this decision. living in hawaii, the usual style of clothing is cool and comfortable, and i am at ease going out in public without any prostheses, besides the hawaiian dress called the muumuu helps to hide all the different body shapes and sizes....

Lonnie Q

Verbal Revealing/Verbal Concealing

Shifts in Friendship and Workplace Relationships Several women wrote on the message board about family conflicts where some family members felt stigmatized and refused to talk about the inherited breast/ovarian cancer in their family. Many more women posted about dilemmas they experienced regarding with whom they could be open and honest regarding their PM. They indicated a lack of trust in how their friends would react. RY found that her friends could not keep a secret but passed it on instead. None of the women used the word stigma, but talked about negative reactions or having to offer complicated explanations for their PM decisions. But as Goffman stated, a “discreditable stigma” is knowable, and the knowledge eventually is revealed and has to be addressed. In order to help “cover” the true situation, the women devised white lies that were close to the truth. They told about pre-cancerous conditions.

RY realized that in some sense she was stigmatized by her decision to have a PM. She says that unless she gave what her friends felt was a compelling reason, they thought she was “nuts.” Thus she had to renegotiate her identity with a white lie, the precancerous condition, and re-present herself with an acceptable explanation for her operation.

Liza, your suggestion about saying it was “precancer” and that due to family history the pm is recommended is also a good choice for me. I’ve found when telling friends, that if I don’t follow up with a compelling reason, such as the BRCA 1, they think I’m nuts. The precancer excuse may give me a compelling reason without having to disclose my genetic status! Randi, I have also found that some close friends haven’t been able to not share this important info with their close support system. At first I was soooo disappointed in them not keeping my confidence, but have forgiven the discretion by remembering they also have to process their feelings regarding this very emotionally charged issue.

RY

A few of the women had bad experiences telling others about their PM and did not want to expose themselves to negative and stigmatizing comments. Randi recalled that most people were horrified that she had done this to herself. She chose what Goffman refers to as taking the discreditable stigma route. She chose an alternative narrative that she felt would present herself in a more favorable light and would, therefore, need to keep hiding her PM by managing information.

Zoe—Let the urge pass and DON’T tell anyone else. I am in the closet like you and wish I had told even less people than I did. I really don’t want the “lookie loos” nor do I get any pleasure from the ‘support’ of others. Most people are horrified that I did this to myself

(including a first cousin whose mother died of breast cancer). Just lie about it, say you had the flu, that it’s a bad year whatever, I have a few friends who figured out something was going on, but stopped asking and forgot about it after a few weeks....

Randi

Intrusion into Mother/Children Relationship Disclosing to children their own BRCA+ status and choice of a PM has additional implications. Several women wrote about not wanting to frighten their children and have them worry that they would lose their mother. Caitlin wanted to ensure the privacy of her son. She feared that he would face unpleasant fallout from gossip if she disclosed information about her PM to her wider circle of friends and acquaintances. Thus, Caitlin also chose what Goffman refers to as the discreditable route rather than the discredited one. She, however, considered the FORCE message board a safe place to tell the truth about her choices and feelings. Women on the message board kept reiterating this theme. The befriend/tend function (Taylor et al. 2000; Taylor 2002) was keenly appreciated by the posters.

Dear Josie, Choosing a pm is an enormous step, and anyone outside of our arena may have lots of difficulty processing it. I had no interest in having my general work place aware of the details of my surgeries.... Also for the privacy of my son, and my not wanting him to think he had a mother at risk of leaving him anytime soon, I had no interest in this being PTA chatter either. I am however a fairly active and grateful participant of this board, where I am most comfortable discussing life with a mutation and all its ramifications....Best,

Caitlin

Telling pre-teen and teenage daughters involves the additional dimension of femininity and sexual attractiveness. It is particularly difficult for an adolescent girl who is beginning to develop her own breasts to adjust to the fact that during this time her mother is undergoing surgery to remove her breasts. Katya poignantly writes about this. Katya’s breast cancer diagnosis was an intrusion into, and an interruption of, her previous relationship with her daughter at a sensitive time of her development. Her daughter’s comments that she would be embarrassed if her mother lost her breasts when she was just developing her own seemed to indicate that the daughter would feel a stigma on behalf of her mother.

...When I told my 11 year old daughter about the results of my genetic testing and explained to her what my follow-up options might be she said something that deeply touched me. She said that she would be embarrassed if I lost my breasts because she was just

getting hers and it wouldn't be fair. I asked her why she chose the word embarrassed and she corrected herself and said that she actually meant that she would be sad. Looking back on my own response at age 12 to my mother losing her breasts—I can see that she probably did mean both embarrass and sad.

Katya

Cognitive and Emotional Reassessment: Coming to Terms with the PM Decision

Gradually, most of the women came to terms with both their BRCA+ status and their post PM self. Despite the complaints and dissatisfaction with their reconstruction that many of the women wrote about, the overwhelming majority of women stated that the freedom from fear and the diminution of risk was worth the problems associated with their PM. They reassessed their cognitive and emotional perspective over time. RY, as well as several other women, felt that as an extra bonus they ended up with breasts that looked better and had a sexier shape after the reconstruction than before. RY, who missed the sensation in her breasts and had a rough reconstruction period with several operations, viewed her good outcome as compensation for all she went through and gave up.

Faye....After two kids, nursing, and 39 years, my breasts were also kind of stretched out and saggy. I have to admit that sometimes I feel a little guilty for enjoying the great way my new breasts look in clothes. I even feel that I have a sexier shape without the clothes (although, of course, there is no erotic sensation). I enjoy the perkiness, the fullness, and not having to ever wear a bra! My husband likes it too! I try to look at it as compensation for everything I've gone through and gave up!

RY

Sally was just beginning to consider being less concealing about her PM. While she still chose to remain silent, she wrote that she admired the women who were able to be open about their PM and who helped educate the public as a result.

I just want to applaud all the women who have chosen to be open with their very personal issues and help educate and inform the public in the process. I have tended to be very private up til now—time will tell what I do in the future....

Sally

Caitlin probably reflected best the views of most of the women when looking back at their PM experience. She

wrote, “....I feel comfortable that I have done and continue to do all that I can to reduce my risks and be here for my family”

Discussion

Goffman and Charmaz primarily applied their concepts to illness and mental and physical disabilities. While a PM does not fit neatly into either category, it has sufficient parallels to allow application of their concepts to gain a greater understanding of the situations faced by women from HBOC families. Many of these women's presentations of self after a PM were affected by changes in their breasts – looks and feeling – that influenced their self-image and their willingness to disclose the PM to extended family, children, friends and co-workers. Weitz (2004) in her book *The Sociology of Health, Illness, and Health Care: A Critical Approach*, concludes that: “Those whose bodies differ in some critical way from the norm must develop a self-concept in the context of a culture that interprets bodily differences as signs of moral as well as physical inferiority. The resulting stigma leads individuals to feel set apart from others” (p. 177).

The women in this sample did not explicitly use the word stigma, but their decisions not to disclose their PM and their use of clothing to hide their breasts, especially during the reconstruction period, indicated a discomfort in revealing their operation to acquaintances and co-workers. They usually felt more comfortable about revealing to very close friends. Currently, PMs are more familiar to the general public than they were in earlier years because of the increase in knowledge and media coverage about hereditary breast cancer. But these women were early adapters and, thus, found it difficult to determine how a friend or co-worker would react. Some women in our sample complained that their friends could not keep a secret and the information about their PM “got out.” The reaction from others was unpredictable and this made it difficult for the women to take a chance with revealing themselves. Yet a few women wrote about misunderstandings that were cleared up when they carefully and completely explained why they chose to have a PM.

We saw examples of both “passing” and “covering” in our data. Non-disclosure was the main way the women chose to “pass.” In addition, some women used what we call a hybrid form of passing/covering by using a close approximation of the truth, e.g., an operation for a pre-cancerous condition. They felt that it was easier to disclose a cancer related mastectomy than a prophylactic one. Individuals who were not members of high-risk HBOC families sometimes had difficulty in comprehending why a woman would remove “healthy breasts” and found this type

of preventive surgery abhorrent. Therefore, some women presented an alternative, and what they considered to be a more acceptable, pre-cancer narrative.

Clothing that hid scars and the shape of breasts was used to “pass,” as were prosthetics. Clothing was also used to “cover.” One of the women years after her surgery wrote about how she still felt uncomfortable naked when she was intimate with her husband, even though he did not mind. She wore a tank top, or a camisole, to deflect her husband’s attention from her reconstructed breasts. Another woman who did not reconstruct felt comfortable in her environment where wearing loose fitting clothing was the norm.

The issue of potential stigma may be one of the reasons women expressed their satisfaction and happiness with the FORCE message board. They wrote about the way that they can be completely open about their decisions and emotions and were completely supported. They did not have to worry about any potential stigmas and negative reactions.

Charmaz (1991) wrote about the self in terms of relationships and time during periods of chronic illness. But most of the women in this study faced “chronic risk” rather than chronic illness. There are similarities, however, between these two situations (Kenen et al. 2003). In Charmaz’s terms, many of these women prior to a PM, are trying to prevent their past and future from consuming them. Their thoughts about the past are filled with memories of family loss, and their future is clouded with concerns about their own premature deaths (Kenen et al. 2003; Lloyd et al. 2000; Hopwood et al. 2000). This is true for women who already developed cancer as well (Ohlen and Holm 2006). Women with a high risk for inherited breast/ovarian cancer experience what Charmaz calls a “dreaded future.” Undergoing a PM provides them with an “improved future.” But their “taken for granted future” is gone. The women on the FORCE website expressed these themes and repeatedly emphasized the value they placed on their “improved future”—one that reduced their cancer risk by 90%.

The women realized that they paid a high price for their PM decision in terms of physical pain, mental anguish, shifts in social relations and feelings about themselves. As Lloyd et al. (2000) concluded, “The surgery meant that women were faced with having to renegotiate their identity where they felt less of a woman, and accepted a new identity with significantly reduced cancer risks” (p. 482).

The events surrounding genetic counseling, genetic testing, the PM and reconstruction appeared to be the times, events and experiences that became anchored to the selves of the women in this study. The earlier chronic intrusive thoughts and interruption of normal life during the PM and reconstruction period were over, but the marks on their bodies and lack of sensation in their nipples and

breasts remained with them and reminded them of the past and their former taken for granted future.

Subsequent to their healing from their final reconstruction operation, most of the women stopped posting and several specifically said that they wanted to move beyond the threat of a cancer dominated life. Despite moments of sadness, but not regret, the women in this study who chose a PM felt that they made the correct choice in doing whatever was possible to live in an “improved future.” They were willing to pay the price of lost body parts and loss of some sexual pleasure for a future free of the previously encompassing fear. Their aim was to return to normal and they achieved this as much as possible.

Limitations

Certain limitations are inherent when relying on messages from a publicly accessible website as data (Jacobson 1999). Individuals posting on the PM threads who discuss self-image, self-disclosure and stigma might not reflect the collective views of either those posters who do not mention these issues or those who read the messages but do not post. While web based support group data has the advantage of being natural, rather than in response to researchers’ questions, the disadvantage is that the researcher is not able to focus questions and probes regarding specific issues of interest. Furthermore, this is a small, exploratory qualitative study and the findings cannot be generalized to the larger population of women carrying a BRCA1/2 mutation. In addition, for this type of qualitative analysis, there can be more than one measure of reality that is objectively grounded.

Clinical Implications

The influence of the larger social context on women from HBOC families is a neglected area of investigation and requires both further research and a greater understanding by geneticists, genetic counselors and genetic nurses working with high-risk women. The experiences of these women living with PM highlight some often neglected psychosocial issues that need to be taken into account in decisional support and follow up of other women in this predicament.

Results from this study indicate that worry about how their PM decision is received colors the women’s relationships with individuals in her social world—colleagues, acquaintances, church members, etc., in addition to family and friends. Whether or not to disclose a PM becomes problematic for some women. Thus, the content of counseling courses required of health professionals caring for women from HBOC families should be expanded to

include the effect of other members of a woman's social world. Furthermore, because the norms of the society are involved, simply counseling the women from HBOC families is not sufficient. Interdisciplinary approaches to the education of other professional groups and the general public are also required to ease the path of women from HBOC families who choose the PM route.

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